



Impact of Care Home Design on Wellbeing and Social Connections of People with Dementia During the COVID-19 Pandemic

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Abstract

The functionality, well-being, and quality of life of people living with dementia can be positively impacted by careful environmental design. As a consequence of the COVID-19 outbreak, sudden rearrangements were made in the social and physical environment of dementia care residents. The present study aimed to explore the lessons learned regarding the design and use of the built environment during the COVID-19 lockdown and to find how the built environment might contribute positively to improved well-being, and social and physical connection of dementia care residents in the future. In a mixed-method explorative study, social-physical aspects of the built environment that influence quality of life during the COVID-19 pandemic were explored. In general, buildings with a spacious layout and flexible use of spaces contribute to a higher quality of life and level of resident well-being, improved infection control, greater resilience, and enhances social and physical contact. Currently, the buildings of many care facilities are not designed to

accommodate a severely infectious disease outbreak. Additionally, nursing staff have learned the importance of attending to the number of stimuli in the social and built environment and attuning these to individual, instead of group needs. Our findings indicate there is a need for designing and building spacious long-term dementia care facilities that allow for flexible, social and personalized appropriation of spaces.

Keywords

Built environment · Dementia · Quality of life · Well-being · COVID-19 pandemic · Social contact · Affective touch · Care home

1 Introduction

Architectural design of long-term dementia care facilities plays an important role in the life of people with dementia [1]. When done well, design is a non-pharmacological intervention, reducing agitation, anxiety, conflict, confusion, and depression, while improving familiarity, orientation, pleasure, mobility, and all activities of daily living [2]. Thoughtful design of the environment can improve dementia residents' social wellbeing [3], positive social interactions [3, 4], affect [5], and behavioral health [6], as such impacting their well-being and quality of life positively [7, 8].

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The outbreak of a new and deadly virus, however, has meant that all care facilities had to adjust fast. To prevent and control the spread of the COVID-19 virus, many care facilities implemented restrictive measures, including severely limited visiting policies, mandatory social distancing, and a rearrangement of living and social activity spaces. In this paper, we want to draw lessons from the COVID-19 pandemic and its associated measures in the context of Dutch intramural care facilities [9–11] to help us better understand how environmental design can contribute positively to improved infection control, and prevent negative side effects on the health and well-being of dementia care residents [9, 12]. It is evident from literature that the built environment has a significant impact on the functioning and well-being of dementia care residents [2, 3, 6, 9, 13–24]. In addition, the social distancing, mobility restrictions, and restrictive visiting policies had a pronounced effect on the opportunities for interpersonal social contact, and particularly interpersonal touch. Providing interpersonal social touch is of significant importance for persons with dementia and crucial for feelings of belongingness, happiness, and communication while suffering from impaired reasoning and responsiveness [25].

With the dramatic reconfigurations in the design and use of physical and social spaces, the pandemic has become a de facto challenging “natural experiment” that gives us the opportunity to rethink the role of the built environment and the importance of social contact for the person with dementia living in it. The pandemic and its related measures therefore probes awareness around issues of quality of life in dementia care facilities and the impact of trade-offs in choices made focusing on safety and physical health versus choices made focusing on quality of life and feelings of well-being [26]. The design of buildings, however, is unlikely to be the single solution to improve quality of life of residents of dementia care facilities; we are aware of the need to facilitate and explore warm technology solutions to support the caring and social environment of the person with dementia living in these buildings [12, 26].

2 Methods

2.1 Design

In this study, social-physical aspects of the built environment were explored that influence well-being, social interaction, affective experiences, and quality of life of residents in dementia care facilities after the onset of the COVID-19 pandemic in March 2020. We used a mixed method approach, combining an online survey of staff working in a variety of dementia care facilities in the Netherlands, randomly selected throughout the Netherlands, with complementary observations of dementia care residents. While the online survey probed a representative sample of staff on a broad range of issues, including social contact, the (changes in) use of various spaces, and the impact of social distancing measures, our participatory observations allowed us to gather more in-depth, richer information on the behavior, changes in the layout, social interactions, and use of spaces in dementia care facilities that were a consequence of implementing safety or distancing measures during the COVID-19 lockdown.

2.2 Online Survey

Participants. The online survey was completed by a total of forty-six dementia care professionals. With the selection criteria “*nursing home*” & “*care home*”, “*Dementia*”, & “*Alzheimer’s disease*” 60 regular Dutch dementia care facilities were randomly selected and contacted from 620 results on the website Zorgkaartnederland.nl, a Dutch website with a database for all dementia care facilities in the Netherlands. Additionally, 40 private Dutch dementia care facilities were randomly selected and contacted from 449 results that were found with the selection criteria “*privately funded*”, & “*privately funded residential care center*”.

Setting and Materials. The online survey was administered through LimeSurvey with open and closed questions structured in several categories, including: general questions on the period

after March 2020, demographic questions, questions about the people residing in the living room or department of the care facility, about the residents and their well-being during the covid-period, the visits from family and friends, the care professional, personal experiences with the governmental restrictions regarding visits and social distancing, and finally some questions on the built environment.

Procedure. The randomly selected regular and private dementia care homes were each contacted by phone, after which the head nurse of each care facility was invited to participate in the online survey through a personalized email.

2.3 Participatory Observations

Participants. Seventy-six dementia care residents were observed across four dementia care facilities located in the South of the Netherlands. In total, 19 males were observed as well as 57 females. For the observation one researcher visited 4 dementia care facilities, either one location per observation was picked as the subject of the observations, or one resident per observation was selected as participant if the resident was mobile and moved around.

Setting. At each care facility, either the living room, an alcove, a communal room, or a terrace outside was chosen as location for the observations. Residents using the room were observed or individually discretely tracked across the facility/department, depending on the movements of the residents within the care facility. The majority of observations were made of residents (socially) interacting within the described locations of the care facility.

Materials. The observations were partially structured with an observational scheme. To create the observational scheme, the MEDLO tool (the Maastricht Electronic Daily Life Observation Tool) [27–29], the observational scheme previously used by one of the researchers during her undergraduate degree for observing people with dementia in a care home facility [30], and Zeisel's [31] chapters on observing physical traces and observing environmental

behavior were used as a basis. For detailed specifications of the observational schemes used during the observations see Coppelmans [32].

Procedure. Residents of the four dementia care facilities were observed during their entire day. Using the observational scheme, partially structured notes were taken on the (social) interactions within the room, the use of the space, levels of engagement, facial expressions, gazing behavior, and atmosphere. Furthermore, a sketch of the floorplan was made with the location of furniture, doors, and windows, which was used to indicate where the interactions took place and to indicate the lines of sight and walking trajectories of persons using the room.

2.4 Data Analysis

Thematic analyses were used for analyzing the open questions of the online survey and observation data, using a combination of Boeije's approach [33] and Braun and Clarke's approach [34]. The thematic analyses were carried out by two researchers independently, and later combined and reviewed in discussions within the research team.

2.5 Ethical Considerations

The online survey and observations were both approved by the ethical board of the Human-Technology Interaction group in Eindhoven. Informed consent was provided by care professionals for the online survey as well as the observations. Both studies were performed on a voluntary basis and there was no compensation.

3 Results

The responses to the questions in the online survey covered a broad range of opinions and observations, within the topics. The responses were individually inspected per question which led to several insights that fit within the themes.

3.1 Thematic Analysis

The thematic analysis of the responses to the online survey and the observations of residents with dementia in long-term care facilities yielded seven overarching themes, which will be discussed next.

Theme 1: Nurturing a Balance Between a Serene Versus a Lively Atmosphere in the Living Room. Nursing staff reported to experience more calm residents during the Covid-19 lockdown, during which visitors were not allowed in the dementia care facility, group activities were no longer provided, and residents could not go outside. This calm atmosphere among the residents seemed, to their mind, to be beneficial for the residents and has made nursing staff more aware of the number of stimuli the residents are exposed to and attune the number of stimuli to the needs of individual residents.

For some residents the absence of (for them) strangers in the living room caused a more calm atmosphere (Online survey)

Those care facilities that are no longer welcoming visitors in the living room of the care facility have seen an increase in the use of the bedrooms and the garden. The function of these spaces has therefore changed. As a result, some care facilities have made adjustments to the garden during the Covid-19 lockdown to welcome guests. Other care facilities have adjusted the built environment such that residents have a choice to go to a calm space or a more lively space when seeking social contact.

Overall, nursing staff of dementia care facilities have become more aware of the sensory and social stimulation residents are exposed to, where they originate, and how they may be balanced according to the needs of individual residents.

Theme 2: The Built, Natural & Social Environment Facilitates and Sets the Mood. Nursing staff report on a range of experiences related to the relative confinement to the built environment during the Covid-19 lockdown. As residents were not allowed to go outside, and sometimes even had to stay in their bedrooms as much as possible, it became obvious that for

some care facilities the built environment facilitates the needs of residents and staff, whereas in other care facilities residents and staff experienced difficulties and found that the built environment is lacking. Nursing staff reported a renewed appreciation of the importance of a good spatial layout and a spacious design of the built environment, both for its functional flexibility as well as its atmosphere. Having a spacious design facilitated flexible use of spaces in times of need, making infection prevention easier, and was said to be enjoyable for residents as it can stimulate and foster social contact and affective connections. Some nurses experienced that the living rooms were in fact too small, a fact that care professionals became (more) aware of during the COVID-19 pandemic. Indeed, during the observations nursing staff were seen to be struggling to move around in the living room of the care facility, maneuvering themselves around wheelchairs, walkers, and furniture in the room. Also, easy, ground floor access to a secluded garden is much appreciated by nursing staff. Frequently, the garden was upgraded to be able to seat more guests and in some care facilities the garden was made weather-proof. Some care facilities created seating in the hallway so that residents could choose to sit somewhere quietly or partake in an individual activity if they wish to. Others created a separate visitors' room. Finally, private nursing homes (often) have a more spacious layout allowing them to make changes within a room more easily as compared to regular nursing homes, and also more often have access to a garden.

Theme 3: Shift in Focus from the Best Interest of the Group to the Best Interest of the Individual. In the absence of otherwise organized activities, and outside visits, nursing staff could pay more attention to the residents and their individual needs. As a result, a shift arose in focus from the best interest of the group to the best interest of the individual, with nursing staff being able to give residents more individual attention. Nursing homes reported to have realized that there is room for improvement in providing person-oriented care, taking a more

personal approach in caregiving, and better attuning to the needs of individual residents, with the realization that they unintentionally had not been attentive enough to the needs of individual residents before the lockdown.

We should learn from the lessons learned during COVID-19, how can we welcome visitors while considering the needs of the resident and the other residents of the group. We should customize for every resident, making agreements with family, about their visit, where, when, and how long. We should explain, make clear why we chose something in the best interest of their loved ones. Person-oriented care is very important, including personal histories, we should document personalities (Online survey)

Moreover, with fewer distractions, nursing staff have become more aware of the care needs of residents with dementia, especially regarding their personal needs in the regulation of the number of stimuli in the environment and their needs in physical and social touch.

Residents always longed for social contact, socially and physically, touching remains important (online survey)

Theme 4: Awareness of the Importance of Social Touch and Closeness to Loved Ones. Having to be socially isolated to prevent infection with the COVID-19 virus, nursing staff, family, and residents have all realized, more than before, that social contact is necessary and that people should not be restricted from it. As nursing staff were advised against giving hugs or holding hands with residents, many of the residents were deprived of social touch and residents were reported to experience touch cravings [“huidhonger”]. Respondents of the online survey shared that social touch is a basic need that is very much needed in times of distress, like during a pandemic.

Residents are touch starved. They miss receiving a hug (Online survey)

During the observations, furthermore, residents often initiated affection, social touch, holding hands and hugging, and so did the nursing staff.

She walks to the woman in a wheelchair, talks to her, brings her head close to hers and holds her hand. She chats with the woman, both smile, she stands up straight and chats some more, both are smiling again, she walks away (Observations)

There is considerable individual variation in how the lockdown was experienced, and the relationships between residents and their loved ones has been impacted variously. Some residents have experienced a great loss in the absence of visitors and otherwise organized activities. They have experienced feelings of loneliness, boredom, under-stimulation, alienation, and incomprehension in missing their loved ones and daily activities. Some further deteriorated in their disease of dementia due to the changes that have been made for infection prevention, especially those with more advanced stages of dementia who no longer recognize their relatives. In contrast, some residents with dementia flourished during the lockdown. With the lack of visitors and activities, nursing staff saw a revival of these individuals and they even seemed to be doing better than prior to the pandemic. Accordingly, for some residents their social bonds have strengthened, whereas for others they were weakened or remained unaffected. A number of relatives reportedly lost some of their affective connection with the person with dementia, leading to personal distress. Social touch and closeness to loved ones are very important for people with dementia. The visits themselves have changed as well, now being experienced more consciously. There is more attention for the resident during the visit (not being able to sit in the living room with other residents and family) and this has sometimes led to the development of new activities and stronger family ties.

I think that visitors are now more involved with their individual loved one, that sometimes new activities have developed, like walking. When the conversation is sometimes difficult, this is a nice activity that does not require much talking, but sometimes it is more difficult, if it is difficult to make contact. Then visitors can no longer contact us in the living room or connect with another resident (Online survey)

All in all, the restrictive measures of the Covid-19 lockdown have led to the realization of the importance of social touch and closeness to loved ones and they have impacted the life of residents and their family dramatically differently.

Theme 5: Compensating the Restrictive Measures and the Consequences of Covid-19 Lockdown. Nursing staff have tried hard to accommodate the absence of visits and activities in various ways. Respondents reportedly engaged in more social contact, giving extra individual attention, offered warm care, hosting more activities in the living room, and offering alternatives to facilitate contact with relatives.

It was a tough period of time, but overall there was much understanding. Video calling, contact through the window, contact in a tent with a microphone, contact across a hedge in the garden. We have tried many things to still allow some contact. However, real, physical contact, a quick hug or a social touch, which is very important, was very much missed (Online survey)

Families valued being kept informed about the well-being of their loved ones and worried that their loved ones would no longer recognize them. Many residents, on the other hand, did not understand the alternative visit and became more agitated and frustrated by the lack of intimacy and touch. Other residents, however, did enjoy the alternative means of social contact.

We tried everything to establish warm contact, but real physical contact, like a hug, the inability to touch, was a great loss (online survey)

Theme 6: Resilience of the Nursing Staff After Experiencing a More Complex and Diverse Role During Covid-19 Lockdown. The Covid-19 pandemic was clearly challenging for nursing staff. In addition to the long hours, and the specter of the disease taking its toll on the most vulnerable, the outbreak of COVID-19 also meant that everything in the care facility suddenly changed—physical structures, work processes, and social interaction norms. Residents with dementia did not recognize care staff wearing masks, face shields, gowns and aprons, and communication was impaired as it was difficult for residents to hear the care staff and emotions were hard to convey through the

personal protective equipment (PPE). Nursing staff had to invest more time in cleaning, guiding alternative visits, and arranging activities for residents in the living room. On top of that, there was fear of infection with a serious yet unknown virus and nursing staff had to sometimes deal with frustrated family members, which made them feel like having to be a police officer.

Finally, the passing away of residents during the lockdown was intense and heartbreaking. The role of the nursing staff was therefore more complex and diverse with a higher workload, more emotional ups and downs, and extra non-medical responsibilities during the global pandemic.

My work has not changed, and I enjoy to keep going. I am glad that family is allowed to come visit again and that restrictions are starting to lift. What personally really hit hard was the process of passing away of residents (Online survey)

Nevertheless, many respondents also look back on this difficult period with positive feelings, such as feelings of strong collegiality, accomplishment and collective pride. They feel they managed to get through this period together as a team and have a positive view of their future in caregiving.

Theme 7: Clashing Values in Caregiving: Safe Care Versus Warm Care. Inherent to many of the experiences that were reported was a fundamental tension between on the one hand wanting to keep residents safe and prevent infections with COVID-19, while on the other hand providing warm care, to show affection, and give warmth through social and physical touch, especially when their relatives could not. This tradeoff became especially salient in the social distancing regulations, including keeping physical distance, separating groups of residents, sometimes putting residents in isolation, continuously wearing PPE, and taking extra hygiene precautions.

For some residents a chat is not enough or not possible. They clearly have a need for physical touch in the form of holding hands, cuddling. This was discouraged as much as possible, so it felt like you were not doing right by the resident (Online survey)

These clashing values are not only reflected in caregiving itself, through human interaction, they

are also reflected in the built environment. Many care facilities have made adjustments to the built environment to minimize the risk of infection by seating residents further apart, creating a separate room for nursing staff to change into PPE, or a separate entrance for visitors.

Social distancing was not always possible, our residents need a lot of physical care, you have to stand close. We tried to touch and hug less, but when the residents asked for it we couldn't resist to hold hands or offer a hug.

Throughout the responses of the online survey, the observations and informal chat with the care staff, it is clear that nursing homes have struggled with providing safe care and warm care simultaneously during the Covid-19 lockdown.

4 Discussion

Research to date has demonstrated that the design of one's living environment is extremely important in maintaining good health, social contact, and wellbeing [3–5, 35]. In this paper, we investigate the effects of the COVID-19 pandemic and its associated measures on changes in the built environments of dementia care facilities, and their impact on the experiences and wellbeing of residents and professional carers. We combined an online survey of care personnel with participatory observations at various care locations, in order to draw lessons on how the social and physical environment might contribute positively to improved resident well-being, now and in the future.

First, in the absence of visitors and group activities during the Covid-19 lockdown, nursing staff have learned the importance of being attentive to the level of sensory and social stimulation in the social and built environment of residents with dementia in order to balance and attune these to individual, instead of group, needs. Our insights underline the importance of personalized care for the person with dementia [3, 36]. Secondly, the restrictive measures of the Covid-19 lockdown have led to the realization that social touch, physical contact, and physical

closeness to loved ones are really necessary for the well-being of people with dementia. From this, the third insight of the Covid-19 pandemic follows, which is that the built environment facilitates residents and nursing staff in flexible use of spaces in times of need, easier infection prevention, enjoyment for residents, and resilience of the nursing staff. In many care facilities, however, the built environment is not optimal which has provided struggles with infection prevention and overall atmosphere among the residents. The clash in values in caregiving—especially between a focus on safety and task oriented care versus a focus on social and physical connection and interaction—has become more salient, as reflected by the reported struggles of nursing staff and residents. A spacious and flexible layout with easy access to private and green areas, supports more personal autonomy and freedom to allow for optimal solutions along the warm care vs. safe care tradeoff. Moreover, a spacious layout of the care facility allows for the creation of both private and social spaces, the creation of a two-persons couples room, and space for private items to create a sense of home and familiarity for residents with dementia [3, 17, 20, 37–39]. This is beneficial for the well-being of residents, easier infection prevention, and better working conditions for the nursing staff.

These findings match the already existing literature on the facilitating role of the built environment in the functioning, positive social interactions, and well-being of people with dementia in long-term care facilities [1, 3–5, 7, 8, 13, 18, 23, 35], however, the COVID-19 pandemic has revealed, now more than ever, that residents and nursing staff of many care facilities have to cope with poor physical building design [40]. One reason for this state of affairs is that surface area is costly and financial cuts in nursing home care have led to the optimization of floor plans in the premises [39]. However, confining residents to their rooms, for fear of infection with COVID-19, made dementia care residents vulnerable to the risks of social isolation and loneliness [41]. It has been advocated to spend

money on better environmental design, even before the COVID-19 pandemic, [39], and now it even seems vital; to save lives in the next pandemic, and to reduce stress of residents and nursing staff of nursing homes [40].

A spacious and flexible layout of the care facility is key to provide residents with the option to take a seat in a lively versus a serene environment; the personal autonomy to adjust the environment to their needs. Additionally, the findings of this research support Torrington's [42] claim that quality of life is related to building design. Residents of buildings that prioritize safety and health over social interactions, empowerment and freedom of movement typically report poorer quality of life. Indeed, our results indicate that those care facilities that have prioritized safety and health have endured greater struggles, 'more difficult to handle' residents, and limited endurance of nursing staff. In addition to environmental design being key to improved well-being of dementia care residents, there is a larger on-going movement towards person-centered care and dementia emancipation, where the focus is more on human rights, personal autonomy, meaning and dignity, rather than a pure medical focus on dementia as a disease. Specifically, the built environment can be viewed as a specific opportunity for applying the principles of warm technology in environmental and building design [26, 29, 36, 43]. The lessons learned through the COVID-19 pandemic underline the importance of such a person-centered approach. Future research should investigate the changing care needs of people with dementia in the coming years. As a new generation of more diverse, more empowered and tech-savvy elderly arises, the design of nursing homes and other care facilities should reflect their changing requirements.

built environment might contribute positively to improved well-being in the future. The findings of this research reveal that the built environment facilitates and sets the mood, that the building is not always suited to the current care demands of people with dementia, and that buildings are generally not designed to accommodate a pandemic or any other outbreak of a severely infectious disease. This is why more research should be directed towards the design of the built and social environment of long-term care facilities. We all have realized, more than ever before, that social contact is necessary and that people with dementia should not be restricted from it. Indeed, the absence of social interactions has deeply affected this vulnerable group, whose opportunities to express these needs and take action to meet their unmet needs are limited. Our research highlights the fact that social relationships and physical contact are key to personal wellbeing and underlines the importance of the entangled role of touch in dementia care, not only the task-related touch but especially the benefits of affect-related touch interventions [25, 44–46]. In all, the person with dementia should be put more at the center of attention, should receive person-centered care, attuned to individual needs, and should be able to express and experience physical as well as social touch and closeness to loved ones. In the design of future living residences, people with dementia as well as care staff should be involved. Here too, the adagio of person-centered care—*“nothing about me, without me”*—is a valuable guideline. Only collaboration with people with dementia will ensure future residential design that promotes quality of life, well-being, social and physical interaction, and engagement, while fostering choice and ensuring person-centered care [26, 47, 48].

5 Conclusion

The aim of this explorative research was to find out what has been learned with regards to the built environment during COVID-19 lockdown in long-term dementia care facilities and how the

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